

## Tics and Tourette's Syndrome in children and young people

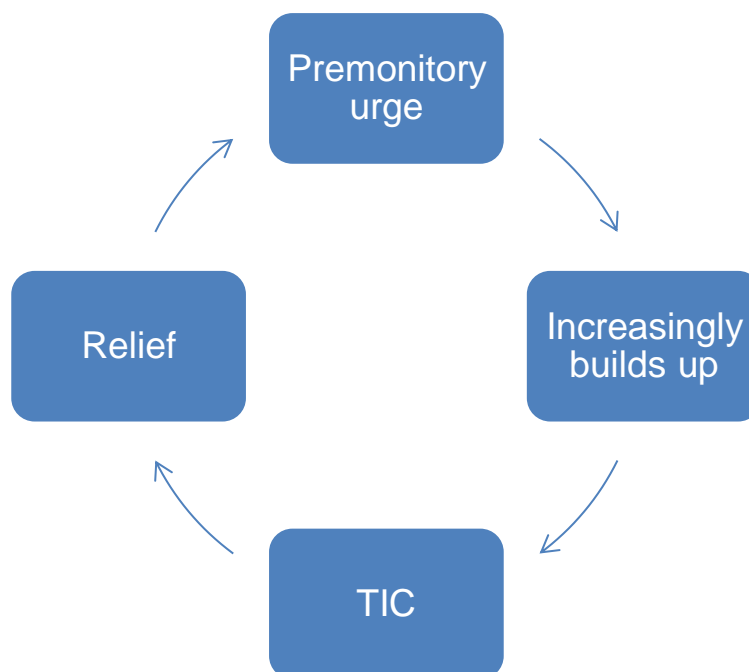
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### What is a tic?

Tics are sudden movements or sounds which get repeated over and over again. They are involuntary (that means the young person cannot help doing them and does not do them 'on purpose') and they serve no apparent useful function.

Different people call them different names, the main ones are tics, twitches and habits.

There is often a feeling before the tic (called a premonitory urge) that is relieved by the tic. The premonitory urge is described differently by different people but includes a feeling of tension, pressure, a tingle, a tickle, an itch or just a funny feeling. The tic may need to be repeated several times until it feels 'just right'. A good way to think about this is when you can feel a sneeze coming and then, after sneezing, the urge goes away.



With practice, tics can be suppressed (kept inside) for a short period of time but this leads to a build-up of tension which is only relieved by the tics. Just like a sneeze can be kept in for a short while but has to come out sooner or later. The longer the sneeze is kept in, the stronger the final sneeze.

The actual tics will tend to vary over time, each one lasting a few weeks or months before changing to a different tic. There can be times where there are no tics but then they may come back. This is called a waxing and waning pattern.

Tics can be motor or vocal/phonic and can be simple or complex. A motor tic is a movement whereas a vocal/phonic tic is a sound. Simple tics involve just one muscle or are just a noise whereas complex tics create a full coordinated movement or are full words or phrases.

Some children and young people have tics which no-one notices whereas others may find them more of a problem.

### Types of tic

Motor		Vocal/phonic	
Simple	Complex	Simple	Complex
Eye blinking	Jumping	Sniffing	Repetition of particular words
Neck jerking	Hopping	Tutting	Repetition of one's own words
Mouth stretching	Brushing hair back	Throat clearing or coughing	Repetition of others' words
Sticking tongue out	Hitting oneself	Hissing	Socially unacceptable words e.g. swearing
Shoulder shrugging	Twirling	Barking	
Spitting	Smoothing or pulling at clothing	Whistling	
Finger clicking	Touching people or objects	Humming	
Nose wrinkling	Facial grimacing	Squeaking	

### What is Tourette's Syndrome?

In 1885, Dr Gilles de la Tourette named a condition where people displayed a combination of motor and vocal/phonic tics over a long period of time. Most children with tics do not have Tourette's Syndrome although some may go on to develop it. Typically the tics start as motor tics and then are joined by vocal or phonic tics. Motor tics tend to start in the face and head then move to the rest of the body; tics start as simple and become complex. When there is a film or television programme about tics, they tend to concentrate on Tourette's Syndrome and focus on the more extreme, though very rare, symptoms such as swearing and violent motor tics which may occur.

## **What makes tics worse/more frequent?**

Tics happen more often in some situations; these can vary between different people. Common situations which make tics worse are:

- anxiety/stressful events
- boredom
- tiredness
- excitement
- thinking about the tics or worrying about what other people think
- on returning home after school/college (especially if the child/adolescent has been suppressing tics through the day)
- computer games
- during the days before a period starts (pre-menstrual days)
- after eating/drinking foods with a lot of additives in
- after taking stimulants (e.g. caffeine in coffee, cola and energy drinks; methylphenidate which can be prescribed for Attention Deficit Hyperactivity Disorder (ADHD); amphetamine taken as a recreational drug).

Some people find that these trigger more tics whereas other people find they help reduce tics, trial and error finds what makes a difference for each individual.

## **What makes tics better/less frequent?**

As above, these are common triggers for making tics less frequent but may not be true for all individuals.

- Sleep
- Relaxation
- Concentrating on something e.g. reading, homework, art and craft activities
- Playing sport or dancing
- Driving
- Singing
- Fever as part of an infection

## **Who gets tics?**

Tics are very common in childhood, the child or young person is often unaware and they tend to stop by themselves, normally within one year after starting.

Tics are 2 to 3 times more common in boys than girls.

Tics are more common in children and young people who have other conditions including learning (intellectual) disability, autism and Asperger's syndrome and other neurodevelopmental disorders including ADHD.

Tics start, on average, between the ages of 5 and 7 years. It is rare to see tics start before the age of 2 years or after the age of 15 years. Tics peak at age 10-12 years.

During childhood, up to 1 in 5 children will display tics, so in a typical school class of 30 children, 6 will have tics at some point.

### **How many children and young people get tics?**

Approximately 10-24% of school-aged children and young people display transient tics (that is tics which start and go away within 12 months).

Approximately 3% of children and young people display chronic tics (that is tics which last for more than 12 months but are either motor or vocal/phonic (not both)).

Approximately 1% of children and young people are diagnosed with Tourette's Syndrome (motor and vocal/phonic tics which last for more than 12 months).

All races and ethnic groups are affected equally.

### **How do tics get diagnosed?**

There is no blood test, brain scan or other specific investigation to diagnose tics or Tourette's Syndrome.

Diagnosis is by a trained health professional (doctor) – normally a paediatrician, neurologist or psychiatrist – and is based on the description of the movements and/or sounds.

Information is gathered from the child or young person themselves, their parents or carers, school and anyone else who regularly sees them. Observations are also gathered by that doctor when they meet the child/young person and can see the tics for themselves, they will normally carry out a physical examination to exclude other disorders.

Other possible causes for the movements or sounds need to be excluded first. Then the tics can be diagnosed and thought can be given into how much impact the tics have. Associated conditions (see below) then are looked for. How well the child or young person is getting on at home and at school is also looked at.

### **What else could it be?**

- Fidgeting
- Compulsions
- Tremor
- Mannerisms
- Seizures
- Other movement disorders (e.g. chorea, dystonia, akathisia)

- Stereotypies (repetitive movements seen as part of autistic spectrum disorders or intellectual disability)
- Allergies (e.g. for repeated sniffing or coughing)

### **Why did my child get tics?**

Tics and Tourette's Syndrome are neurological disorders. The exact cause of tics and Tourette's Syndrome is not known.

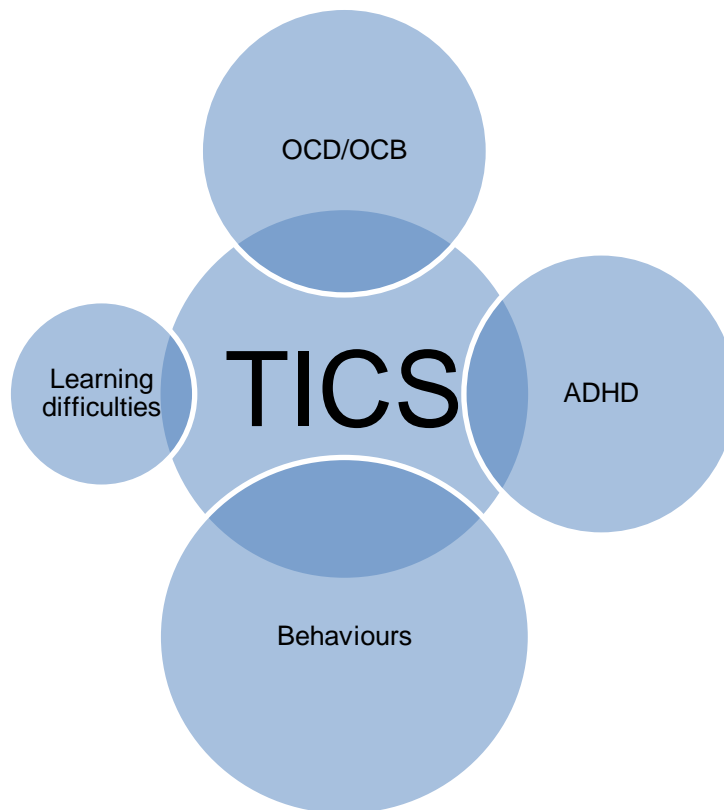
However there are various theories which include:

- Genetics
  - A child is more likely to develop tics and Tourette's syndrome if they have a parent or sibling with them. But this is not guaranteed, many children with tics have no family members with tics, equally many parents with tics do not have children who display tics.
- Neurological
  - Some studies suggest that brain chemicals (neurotransmitters) may be involved. The most likely ones are dopamine and serotonin.
  - Some other studies suggest that minor defects in the structure and working of parts of the brain may be responsible. The area focused on are the basal ganglia.
  - There is not strong evidence for either of these theories yet.
- Pregnancy
  - It is not conclusive but possible that problems during pregnancy or childbirth may increase the risk of tics. For example prolonged labour, high levels of maternal stress during pregnancy and very low birth weight babies.
- Infections
  - It has been hypothesised that infection with streptococcus (a common bacterium) may lead to an autoimmune process which can cause tics.
- Other
  - Some adolescents find that if they use illegal drugs such as amphetamines or cocaine, that these can trigger tics

### **What often goes with tics?**

A child or young person who has tics is much more likely to have other conditions compared to a child without tics. Only approximately 10% of children have 'pure' Tourette's Syndrome with no other clear difficulty. Sometimes, the tics themselves cause very little problem so do not need treatment but the associated condition does cause a problem so may need to be the focus of the treatment.

Most commonly:



Obsessive Compulsive Disorder (OCD) and Obsessive Compulsive Behaviours (OCB) are seen in more than half of those children and young people with Tourette's Syndrome. The compulsions (behaviours) seen in tic-related OCD tend to be related to touching, hoarding and counting rituals.

Attention Deficit Hyperactivity Disorder (ADHD) is seen in nearly half of young people with Tourette's Syndrome; difficulties with attention and concentration (but not enough to be diagnosed with ADHD) are seen even more often. For these children, it tends to be the ADHD symptoms which have greatest impact on their lives. Children or young people who receive medication for ADHD, especially stimulant medications such as Methylphenidate, can display tics as the medication lowers the threshold for tics to be seen, if this is a big problem, it should be discussed with the doctor who is prescribing the ADHD medication.

Behavioural problems including angry outbursts and conduct disorders can be very difficult to manage. These can be seen in more than three quarters of children and young people with Tourette's Syndrome. Several studies have shown that 'rage attacks' or explosive anger outbursts are more common in children and young people with Tourette's Syndrome. These can be set off by what appears to be very minor triggers but if a child has been using a lot of energy to control or suppress their tics, it can take very little to 'push them over the edge'. After the child or young person has calmed down, they are often sorry. General behaviour techniques can be helpful.

Learning difficulties are seen in roughly one third of children and young people with Tourette's Syndrome. They can include specific learning difficulties such as dyslexia or

there can be problems in a child's ability to learn new tasks quickly. There might be a need to organise extra school support, in class or at exam times.

Also:

- Mood disorders such as depression. Children and young people with chronic tics are more likely to develop low mood, whether this is due to the tics themselves or the impact it has on their lives such as bullying is not always easy to work out. Some medications used to treat tics can cause depression as a side effect.
- Anxiety disorders such as generalised anxiety disorder, panic attacks and phobias
- Autism and social communication disorders
- Self-injury such as head banging
- Sleep problems are seen in children with tics and Tourette's Syndrome, for example finding it hard to separate from parents or carers to go to bed, finding it hard to get to sleep and sleepwalking. This is more of a problem if the child is tired at school and if it impacts on the rest of the family. General advice about good bedtime routines needs to be followed and sometimes treatments for the tics themselves can have a positive impact on sleep.



## Red flags

There are some occasions when children and young people with tics need urgent support.

Tics can be painful, if motor tics are particularly strong or violent.

Some tics take the form of self-injurious behaviours and can involve the child or young person hitting themselves or hitting hard surfaces such as walls; tics can also include head banging.

Children and young people with tics can become very self-conscious, embarrassed and socially awkward because of their tics. Other people can be unkind and insult them. Sometimes, children and young people with tics can be bullied because of them. Their mood can drop and they can become sad, withdrawn and sometimes even depressed. They can also develop self-harm as a strategy to try and make themselves feel better.

If a Red Flag is present, then the child or young person needs to access help and support quickly. This can be done via different routes including via school, the GP or direct to local CAMHS (Child and Adolescent Mental Health Services).

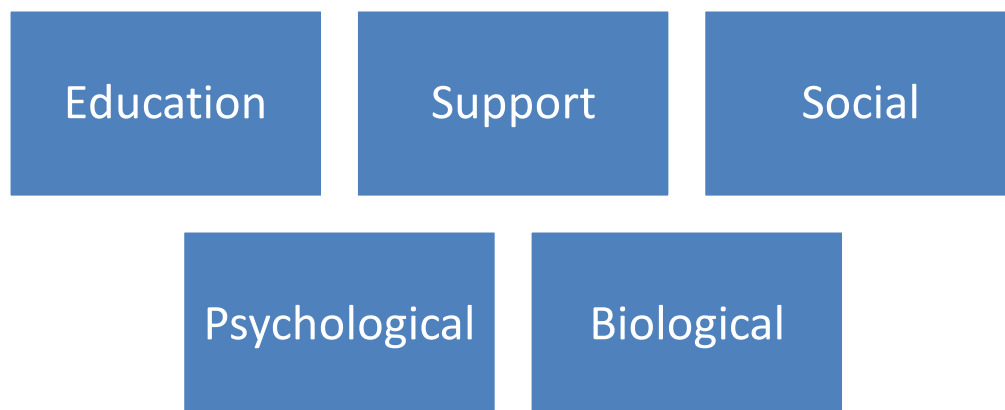
## What treatment is there?

Treatment or intervention needs to be considered for everyone, not just the child or young person who has tics. This includes parents or carers, siblings, teachers and classmates and anyone else who has a significant input into that child or young person's life such as

grandparents or staff at out of school activities (scouts/brownies, music teachers, sports coaches etc).

The tics may not need treatment, but an associated condition (such as those described above) may do.

All treatment plans for children and young people within mental health services look at key areas:



### Education and support

The most important interventions are reassurance, education and support.

Educating the child or young person about their tics can help them feel more in control and also gives them something to say when strangers ask about their tics or people try to make hurtful comments. Children and young people with tics normally go on to have happy and successful lives.

Educating adults and other young people about what tics are and most importantly that the child is not doing them on purpose, cannot help doing them and that the tics should be ignored can be very helpful.

It is often a good idea to make sure that school staff know something about tics, for their own interactions but also for teaching fellow pupils. It can be useful to ask if the child or young person could have a 'pass' or 'time out card' which allows them to leave the classroom for a short while without drawing lots of attention to themselves.

### Social

It is important that any bullying is dealt with. Schools should be informed about what tics are and how to support the child or young person. If there are significant issues within the family which make it harder for the young person, for example parental mental illness, bereavement, substance misuse or neglect, then support from children's social services may be required.



Some parents report positive results from dietary changes, although there is not strong evidence for this, it can be worth trying to reduce foods and drinks which are high in sugar, additives and colouring.

Some people with tics report benefit from complementary or alternative therapies such as acupuncture but this is not supported by evidence.

Many people with tics benefit from going to support groups; Tourettes Action run support groups for children and young people with tics but also for their families.

### Psychological

General psychological support – talking therapy – can be helpful in reducing overall stress and anxiety in children and young people, looking at self-esteem and self-confidence, learning to regulate emotions and strategies for managing low mood and anger. This can also include relaxation techniques which require repeated practice and strategies for how to manage teasing and bullying.

There are also specific psychological or behavioural interventions for tics and Tourette's Syndrome. These include Habit Reversal Therapy (HRT), Exposure and Response Prevention (ERP) and Comprehensive Behavioural Intervention Therapy (CBIT).

These aim to help the child or young person feel more in control of their tics, which not only reduces how often they tic in public but also improves self-confidence. When children and young people successfully learn to hold their tics in (suppress them) in certain environments e.g. at school, they may display more tics when they return home, this is normal. They work best when practised lots of times, approximately half of children and young people report that they are helpful techniques.

HRT aims to teach the child or young person to do other movements or make other sounds which compete with the tic, over time, this should stop the tic happening. It can be used in children and young people who are good at recognising their premonitory urge (the build up feeling). One tic is tackled at a time. The competing response is chosen because it is less obvious or more socially acceptable than the tic. For example – if the tic is a shoulder jerking upwards, the competing movement is to deliberately move the shoulders downwards; if the tic is to open the mouth wide, the competing movement might be to purse the lips and push the teeth together; if the tic is a vocal sound, the competing response may be to take slow deep breaths or swallowing.

ERP aims to help the child or young person become more comfortable with the premonitory urge and, over time, to try and suppress the urge and hence the need to tic. All the tics are tackled together.

CBIT combines HRT with education, relaxation, social support and functional interventions (looking at what triggers the tics or may happen because of the tics).

### Biological

Research studies into medication for tics are sometimes difficult to interpret due to the natural pattern of tic disorders ("Did tics get better because of the medication or because they would have anyway?") and because different people in trials tend to have very different

symptoms which make it hard to compare. There are also very few trials approved involving children and adolescents.

Medications are sometimes used for children and young people with tics but should be considered only for those with very difficult tics, which create a problem for children and young people at school, at home and/or socially, which cause distress (either directly or via bullying) or those which cause physical injury, and only then when they have not responded to other interventions such as those described above.

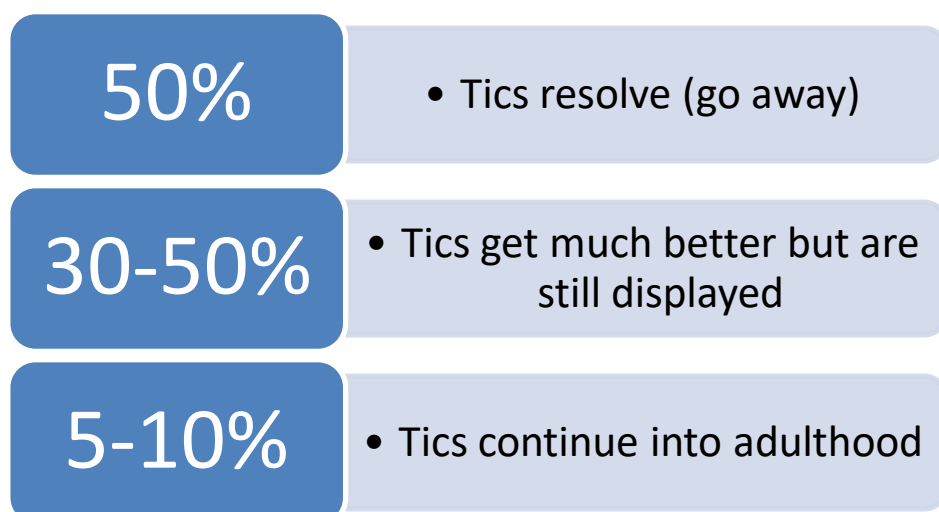
Medications used most often are alpha2 adrenergic agonists (for example Clonidine) and those from the antipsychotics group (for example Aripiprazole, Risperidone). These medications do not come without side effects in particular sedation (sleepiness), weight gain, constipation and problems with blood pressure, the heart rhythm, blood sugar levels and cholesterol. The side effects are sometimes worse than the tics so there needs to be a discussion with a doctor about the balance of risks. Also medication does not always get rid of tics completely, often it just reduces them. Medications tend to work in reducing tics in approximately 7 out of 10 people.

If one of the comorbid conditions is causing significant problems, it may be worth discussing the option of medication for those, although remember they can sometimes cause an increase in tics so doses tend to start small and increase slowly.

Other rare biological interventions are Botulinum toxin and psychosurgery. Botulinum toxin can be used for severe tics, it paralyses local muscles stopping specific tics happening, it has a temporary effect, lasting approximately three months and can cause side effects. Psychosurgery (brain surgery) is used very rarely and only in extreme cases. It is called Deep Brain Stimulation (DBS), it tends to be used in adults and research is still ongoing.

### **Will the tics go away?**

The typical course of Tourette's Syndrome is:



It is important to be positive about the long-term future for children and young people who display tics. There is a good chance that the tics will completely go away or at least

significantly reduce by their late teens/early 20s. Even in those children where tics continue into adulthood, they often become less obvious and less of a problem. However, it is very hard to accurately predict the course during childhood.

The natural pattern of tics is that they 'wax and wane' - that is they seem worse for a period of time, then get better or go away, then after some time they may return again. Some young people find that their tics go away and only come back during times of particular stress for example during exams, when they move schools or start college or are in new relationships.

Some of the associated conditions described above can continue into adulthood, even if the tics themselves have gone away.

### When do I need to seek help?

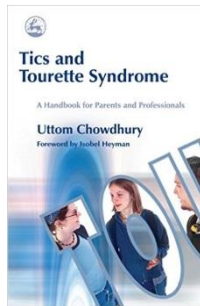
If the tics are mild, do not cause any distress or get in the way of the child or young person's schooling, socialising or family life then the best intervention is probably none except getting information and education.

If however, any of the above is not true, then help can be sought via books, online information, support groups and the NHS – an appointment with the child's or young person's General Practitioner may be sufficient, if not they may make a referral on to paediatrics (a children's doctor), a neurologist (a doctor with special interest and knowledge about brains and nerves) or a child and adolescent psychiatrist.

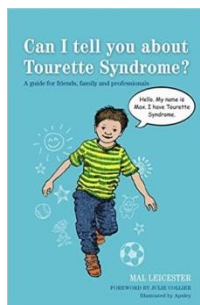
### General Do's and Don'ts

DO	DON'T
Try to ignore the tics	Tell the child or young person off for ticcing
Reassure the child or young person that everything is ok and there is nothing to be ashamed of	Try to stop the child or young person ticcing
Educate others - friends, family, school, general public	Try to stop the tics yourself
Try to decrease overall stress and offer praise whenever possible	Mimic / copy the tics
Encourage the child or young person to take part in normal activities – sports, music, hobbies etc	Worry too much – tics normally go away by themselves

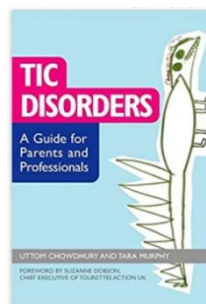
## Books



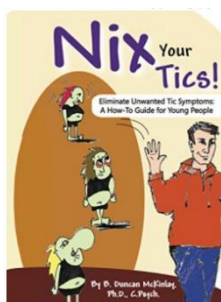
**Tics and Tourette Syndrome – A handbook for parents and professionals.**  
Uttom Chowdhury 2004



**Can I tell you about Tourette Syndrome? A guide for friend, family and professionals.** Mal Leicester 2013



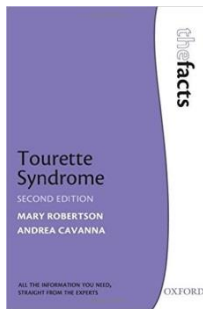
**Tic Disorders A guide for parents and professionals.** Uttom Chowdhury & Tara Murphy 2016



**Nix your tics! Eliminate unwanted tic symptoms – a how to guide for young people.** B Duncan McKinlay 2016 (Kindle edition)



**The Tourettes survival kit – tools for young adults with tics.** Tara Murphy & Damon Millar 2019



Tourette Syndrome the facts 2<sup>nd</sup> edition. Mary Roberston & Andrea Cavanna 2008

## Websites

Tourettes Action [www.tourettes-action.org.uk](http://www.tourettes-action.org.uk)

ACAMH (The Association for Child and Adolescent Mental Health) [www.acamh.org](http://www.acamh.org) topic guide Tourette Syndrome

Tourette Syndrome Clinic at Great Ormond Street Hospital [www.gosh.nhs.uk](http://www.gosh.nhs.uk) and search for Tourette Syndrome

NHS Choices [www.nhs.uk](http://www.nhs.uk) and search for tics

MindEd [www.minded.org.uk](http://www.minded.org.uk) and search for 'tics and twitches' under common problems

Life's a twitch [www.lifesatwitch.com](http://www.lifesatwitch.com)

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